

## **Disability Etiquette**

### **Some Do's and Don'ts From the Parent's Perspective: Tips to Make the Office Visit Better for Everyone**

**The following suggestions have been compiled from parents of children with special health care needs across the country:**

- DO respond positively to our children in your initial interaction. Tell us they are cute, sweet, cool — that they are wearing a neat hat. Let us know that you value them even if you can't cure them.
- DO ask questions of our children, even if the child can't speak. Show your recognition and respect. Don't worry; his parent will find a way to facilitate the communication.
- DO look at our children when you are talking to them. Please make every effort to establish a personal connection.
- DO get down to our child's level. For example, if our child is in a wheelchair, kneeling or sitting down will help make him feel more comfortable.
- DO realize that parents sometimes are very tired of telling their story over and over. Even though you may have your own personal medical interest, don't ask if you don't need to know. Be understanding if the parent shows frustration at telling his child's "story" yet again.
- DO notice and be attentive to brothers and sisters. They have grown up in a situation where their sibling has, by necessity, received lots of extra attention. They don't understand why they shouldn't be just as entitled to a sticker or balloon.
- DO be aware that our grief and sadness may recur at any time and often does at transitional times — beginning pre-school or high school, the day of the senior prom, an anniversary of another loss. It's never resolved entirely.
- DON'T ask questions or raise issues that could be painful for us (and our child) in front of our child. If you need to understand more about the birth history, for example, find a way to talk separately with the parent. You should never assume our child doesn't understand or doesn't have feelings.
- DON'T refer to our children by their diagnosis (e.g., "MR kid", "Downs kid"); it's a good habit to develop no matter with whom you are talking.
- DON'T judge parents; we are doing the best we can under often difficult circumstances. If we are impatient or rude, it may be that we are under particular stress.
- DON'T be surprised if we need instructions, procedures or explanations repeated several times, especially if the information is complicated, upsetting or unexpected. We are often thinking about a million other things and we are trying to synthesize what you have to tell us at the same time.

*Silva TJ, Sofis LA, Palfrey JS, 2000. Practicing Comprehensive Care: A Physician's Operations Manual for Implementing a Medical Home for Children with Special Needs. Boston, MA: Institute for Community Inclusion, Boston.*